



Developing Services for Older People and Their Families

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Chapter 6

'I Was Given Options Not Choices' Involving Older Users and Carers in Assessment and Care Planning

Fiona Myers and Charlotte MacDonald

This chapter explores the reality for service users and their family carers of their involvement in care planning and the extent of the opportunities to exercise choice in how their needs are met.

Central to the rhetoric of community care is the principle of greater user and carer involvement. As articulated in the White Paper 'Caring for People' (Department of Health 1989), and in subsequent official guidance, the objective is to give users and carers 'a greater individual say in how they live their lives and the services they need to help them to do so' (Department of Health, 1989). Nonetheless, there is what could be called a 'hesitancy' apparent in policy statements. While seeking to redress the balance of power there is, at the same time, a recognition that this shift is not absolute. Unlike consumers of other services, for users and carers, ultimately it is 'the assessing practitioner who is responsible for defining the user's needs' (SSI/SWSG 1991, p.53). Further, the involvement of users and carers in the decision making process is not the same as handing over decision making authority or the resources to act on those decisions.

As a number of commentators have noted, there is a potential contradiction between a policy which seeks to promote consumer choice and participation while also seeking to ration and prioritise resources (Allen, Hogg and Peace 1992, Ellis 1993, Caldock 1994). Lloyd (1991), who analyses this tension in terms of competing 'liberal' and 'conservative' discourses, suggests there is an incompatibility between a 'bottom up' approach emphasising the individual's role in defining their own needs, selecting and controlling the delivery of services and, where necessary, able to seek redress, with a 'top down' approach

where 'management' assesses need and allocates scarce and rationed resources.

This tension at the heart of community care policy is not of abstract political or philosophical interest, but makes itself felt at the grassroots level of policy implementation. For frontline workers it can mean, as North (1993) suggests, having to act both as 'neutral advisers' and as 'gatekeepers' to scarce resources. For people seeking support, even if encouraged to participate, the opportunities to act as empowered consumers may be constrained by the limited range of options from which to choose.

Allen *et al.* (1992) found from their study in England, completed immediately prior to the introduction of the new community care procedures, that older people tended to have no choice over what went into their package and that participation was limited to agreeing with what was offered. Given the contradictory nature of the policy, the question this raises is whether, from the accounts of service users and carers, any progress has been made in shifting the balance of power. From interviews undertaken following the implementation of community care, this chapter explores some of the implications of this tension for older service users and informal carers.

The study

The data on which this chapter draws comprise part of a larger Scottish Office funded study being undertaken in four regions in Scotland by the Social Work Research Centre at the University of Stirling. In the course of the study data from a number of different sources are being collected. First, the completion by workers of case monitoring forms for people referred for comprehensive assessment, both at the time of assessment and after a period of nine months (or on case closure), provides information on the social circumstances, identified needs and services provided to 247 people, of whom 144 (58%) are aged over 65 years. Second, interviews with 65 social work department practitioners explored their perspective on the introduction of community care policies and procedures (MacDonald and Myers 1995). Third, users and carers identified through the case monitoring forms, were interviewed about the assessment and care planning process. Follow-up interviews are currently in progress aiming to explore their experience of the implementation of care packages.

The main focus of this chapter will be the responses of the older users and their informal carers, but to set the context it may be useful just to briefly sketch a picture of the practitioners.

The practitioners

Although all the workers in the sample were employed by Social Work Departments, they did not all come from a social work background. Included in the sample were people from nursing, occupational therapy and home care backgrounds, as well as one health visitor and one community alarm organiser. A number of the practitioners had specialist expertise in working with older people. In one region, for example, one worker had been an elderly specialist social worker, another had been a social worker attached to a social work team for older people. But these were in some respects atypical. The majority had previously worked as generic workers, or as specialists in learning disabilities or child care. As a result they were not necessarily experienced in the needs of older people. With the exception of concerns around recognising dementia and the legal implications, this lack of experience was not, however, reflected in their demands for further training.

In terms of their attitudes toward involving users and carers in the process, the majority of practitioners expressed support for greater consumer participation. However, what also became apparent from their comments were the obstacles to realising this goal. Some of these stemmed from the structural constraints within which workers were having to operate, in particular the pre-determined eligibility criteria and the limited options from which to offer people choices. Aspects of practice could also, unwittingly, serve to undermine the involvement of users and carers. For example, workers differed among themselves as to the degree to which they let users and carers see, sign and retain copies of assessment of needs forms and care plans. Third, workers suggested barriers which stemmed from the users and carers themselves, not just communication difficulties, but also difficulties of comprehension on the part of a confused user or someone with dementia. Additionally, workers perceived what they felt was a reluctance on the part of some users to take up the mantle of the informed consumer. Older people in particular were felt to be particularly uncomfortable with the proffered gift of participation. One worker commented,

'For a lot of the older people, part of their need is for someone to do it for them, and not to have the hassle of finding a place for respite or phoning round for care services.'

Other studies suggest that this reliance may be due not to age *per se*, but to the sense of powerlessness on the part of users and carers, and a desire for a knowledgeable and assertive advocate to act on their behalf (Robertson 1993). Meethan and Thomson (1993) also found a tendency for users and carers not only to defer, but to seek to hand over power. This apparent handing over of power may be a positive choice in the way that a 'client' would employ a lawyer or other technical specialist to act as broker, but it may also be an acknowledgement of the asymmetrical power relationships within the welfare market. Workers not only have the knowledge of the market, and the skills to circumnavigate its complexities, but are also keyholders in their own right. As such, users and carers, although encouraged to be partners, may not experience it as a partnership founded on equality.

Users and carers

The users and carers were identified from the case monitoring forms. Workers were asked to approach all the people included in the main study to ask if they were willing to be interviewed. Inevitably with this approach workers will tend to sift out people who they feel would be unable to participate, perhaps because of a communication problem or dementia. People with whom the worker had no further contact or those with whom the worker had a difficult relationship might also be excluded. Identifying an appropriate informal carer may also not be without its problems, as was found in relation to one younger client where the identified 'carer' proved not to be the person caring for the client in the sense of providing physical and personal care. This loss of control over the selection process was, though, balanced by the preservation of the privacy and confidentiality of those users and carers who did not wish to be approached.

A total of 52 users were interviewed, 31 (60%) of whom were aged over 65 years. Of these, over three-quarters were women. Interviews were undertaken with 36 informal carers, 19 of whom were supporting someone aged over 65 years.

Among the carers of older people, four were male and 13 female, the remaining two 'carers' were in fact married couples. In three cases

the carer was the husband of the service user, one was the son and one was a sister. The largest group were daughters caring for a parent, comprising 12 of the sample of carers of older people.

In 10 cases the carer only was interviewed because the older person was felt to be unable to participate. In 21 cases the user only was interviewed, and in 9 cases both user and carer were interviewed. Where carers were interviewed it was to obtain their views as carers, not as proxies speaking on behalf of the user.

Where an interview took place with a user and/or a carer, three quarters of the older service users were living in the community, the remainder were in residential care.

Involving users and carers

Terms like 'involvement', 'participation', 'choice' can mean different things to different people. A worker's idea of involving a user may, from the user's point of view, amount to being informed of a decision made elsewhere. In order to conceptualise 'involvement' a number of commentators have drawn the analogy of a ladder (Arnstein 1969, Taylor *et al.* 1992). Although the descriptions of the different intermediary steps on the 'ladder' may vary, essentially they describe the same process of movement from a low level of participation in which decisions are imposed on an individual with little or no discussion of whether, how, where and when support will be made available, through to a high point of service user autonomy in decision-making and resource allocation.

In the context of assessment and care planning, what is at issue is the degree of power or control the user and carer have over the process and its outcomes. Focusing specifically on access to assessment, information sharing and decision making, the aim here is to begin to explore the degree of control and autonomy this sample of older service users and their informal carers appear to be able to exercise over the process. The findings, at this intermediate stage of the project can only be tentative rather than conclusive: raising questions rather than providing answers.

Getting into the system

Not all the service users specifically sought help themselves, or knew who had made the referral. Of the 31 service users interviewed only two had referred themselves to the social work department. Of the

remainder, fourteen were unsure who had initially made the referral on their behalf. Carers, on the other hand, appeared to be more proactive with eight of the 19 referring themselves and only two not being aware of the source of the referral.

What is perhaps more important is their understanding of *why* the worker contacted them. Among the sample of users most saw the worker's role in terms of seeing what help they needed. Many identified a change in their own circumstances as triggering the worker's involvement: a substantial number of the users had had falls which had landed them in hospital. But other users cited a gradual deterioration in their ability to cope, or a change in their home circumstances. In several cases these older users were themselves 'carers', and as a result of their own ill-health were less able to provide care. There were also users who recognised that the reasons for the worker's involvement stemmed from their informal carer's inability to continue caring. One, for example, described how the worker came to see her about her going into a home because:

'My daughter did not want me in her home...she works most days...(she's) unable to cope with me and her family problems.'

Finally, there were among the service users a few who remained bemused about the worker's involvement. For example, one user who was in a long stay hospital at the time of the interview could not recall the worker being involved at all, and denied that she needed any help. Another service user was unsure who had involved the worker and the reason for the visit:

'I was alright, don't know why she came. I think it was just for a chat.'

The carer in this instance referred to her mother's gradual deterioration and the fact that 'you had to go through social work before there would be any placements for care'.

As this example suggests, some carers had very specific ideas as to why a worker became involved, referring to what they perceived as the user's need for residential or nursing home care. Others cited specific types of help they felt they required to assist them to carry on caring. One carer, for example, who made the referral herself, was looking for respite from caring from a demanding parent. Another needed care to be provided while she went into hospital to have an operation. In a

number of cases the request for assistance amounted almost to a *cri de coeur*, where a carer felt they could no longer cope with caring.

A recent study describes how much fear can be a motivating force for users and carers (Department of Health 1994), while Meethan and Thomson (1993) describe the relief felt by users and carers on entering into the Scarcroft project. What perhaps should not be overlooked is the possibility that a process which is often set in train at a point of crisis, or when a user or carer is feeling at the end of their tether, or 'like a useless article', may in itself undermine people's sense of their own autonomy, or control over their own destiny.

Exchanging information

Given that users and carers are often, as the seekers of assistance, placed in a dependent position, the onus is much more on the worker to redress this imbalance, both through listening and responding to users' and carers' expressed needs and by providing information.

In Allen *et al.*'s study (1992), just over one half of the older people felt they had had enough discussion about what support and services would be most helpful to them. In the current study users, in general, felt that the worker was listening to them and gave them as much time as they needed, as one remarked:

'He let me know he had plenty of time to listen...he was very easy to talk to...I think I discussed all my needs and fears...he's a good listener.'

It could be argued that the apparently high level of satisfaction with workers as people willing to spend time and listen, reflects what Wilson (1993) describes as the public account or socially accepted version, which may be at odds with the private account. However, the responses were not just what Wilson would perhaps describe as 'neutral' polite statements such as 'he's very nice', but quite fulsome praise. One user, for example, described the worker as:

'Very kind and helpful, I call her a friend...she has been a brilliant help to me...I think very highly of her.'

Among the respondents, critical comments tended to come not from users but from carers, and tended to be cases where the carer was seeking residential or nursing home care. In several cases, they felt that the worker had listened to them and been prepared to spend time with

them, but appeared to be slow to get things moving. In other instances the carers felt the workers involved were too slow to understand the pressure that they, as carers, were under. A number of carers felt constrained from expressing their concerns because the service user was present when the worker came to do the assessment.

What this illustrates is the potential tension between users and carers, and their conflicting perceptions of whose needs the worker should be addressing. This emerged most poignantly in one case where the user wanted to stay living with her daughter but the daughter was seeking a residential placement for her mother. In this case the user felt the worker understood the situation between her and her daughter, but nonetheless 'tried to get me to go to a home. I do not want to go there'. The daughter, for her part, felt that the worker 'would have liked my mother to stay here and have...some day care'. In instances such as these, the worker's role may be that of an arbitrator seeking a compromise solution, rather than the desired solution of either party.

Although the users interviewed indicated that they felt that the worker listened to what they had to say, the comments of the workers suggest that not all users were given a voice. This was found in relation to people with dementia who, although able to express an opinion, were not felt able to make an informed judgement. One worker remarked:

'With dementia they don't know what they want and they don't know what's best for them.'

In cases such as these the voice of the carer may not only serve to speak for the user, but also be the loudest in the decision-making process. This is despite, as some workers recognised, the possibility that carers have their own 'agendas'. For users without informal carers the decision-making responsibility may rest solely with the professional. As Fisher (1990) comments, for people deemed unable to make reasoned decisions, 'concepts of choice and participation are nearly meaningless'.

The other side of the coin to being listened to is being informed. Allen *et al.* (1992) found that substantial numbers of both users and carers felt ill-informed about the range of services available. Workers in the current study certainly recognised the importance of enabling people to make *informed* choices. Nonetheless, the comments of the users and carers interviewed suggests that there is a fine line between being 'informed' and being told. In other words, the redistribution of

knowledge which would enable the user and/or carer to make these informed choices, may only be partial. One carer, for example, remarked:

'I was given options, not choices. I was told what was available,' while a user explained:

'She told me what I was going to get and I told her what I didn't want.'

Given that knowledge is power, this dependence on the worker can mean that at the point of decision making users and carers are again unequal partners in the negotiation process.

Decision making

Users and carers may feel that they are listened to, but when it comes to having what they say acted upon where does the decision making power lie? Which voice carries the greatest weight and what are the decisions to be made?

The responses suggest that the degree of influence over decisions, if not the power to make them, may be unevenly distributed between users, carers and others. In some cases a medical decision to admit someone to hospital effectively removes the choice of social care options (at least in the short term). Second, as suggested above, there were instances cited by the workers interviewed where the expressed views of the user might be overridden because they were not believed to be based on an informed judgement. In cases where a user continued to prove 'recalcitrant', several workers suggested they might consider invoking the law to ensure compliance. Third, there were cases, evident among the sample of users interviewed, where residential care was being proposed but the users themselves felt the decision was effectively out of their hands. One user, for example, felt that she had no choice:

'The doctor in the hospital told me I would not manage at home so I had no choice other than to come into this home.'

Fourth, in cases where user and carer disagree, the importance, to a worker, of supporting the carer to continue in their caring role may shift the balance of power toward the carer's preferences, particularly where there is a potential or actual threat of withdrawal of care.

Certainly, several users interviewed felt under pressure to accept residential care because of their informal carer's needs. The comments of some of the carers, however, suggest that they did not always feel that they had any influence. One carer who expected the worker would be instrumental in arranging for her mother to be admitted to residential care appeared resigned to her mother's resistance:

'As my mother is not that far gone it is up to her to make her own choice as to what she wants. I agreed. In the end it is nothing to do with me.'

Fifth, of course, is the influence of the worker themselves. Workers are not only advocates and advisers, but also gatekeepers to resources. If a user's or carer's expressed need does not meet local eligibility criteria or agree with the professional's assessment, then professional definitions may prevail. For example, one user interviewed described how he had wanted to move to sheltered housing, but 'the social worker said I was better off where I was'.

Different participants to the process may, therefore, have different degrees of influence over the outcome. But what of the decisions themselves? Users and carers may feel they are given a good hearing by the worker, but while receptivity to users' and carers' accounts is a necessary pre-condition to consumer involvement, it is not sufficient of itself. Arguably, the touchstone of 'involvement' is the scope which users and carers have to make choices in terms of the needs to be met and the means for meeting those needs. Allen *et al.* (1992) concluded that most of the users and carers in their study had no choices either about what, if anything, went into their package, or about who provided this service and in what way. In so far as consumer choice was exercised it was through refusal or by choosing to discontinue a service. The scarcity of resources was seen by workers, users and carers as putting limits on user/carer decision making powers. Allen *et al.* concluded that 'positive choice among consumers was not really encouraged, and in some cases, was treated as undesirable'.

From the current study, too, it became apparent that, at the point of service provision, for users and carers there can be a number of different levels of decision-making power:

- no opportunity to choose: users and carers are advised what they can have, with only the negative power of refusal (if deemed able to give informed consent);

- opportunity to choose from a limited range of available or pre-determined options;
- opportunity to develop their own package, with the worker acting as broker, or user and carer having delegated authority to make decisions and access to resources.

Levels one and two seem to characterise the experiences of the users and carers interviewed in our study.

Where the decision is between a residential or non-residential care plan, this may ultimately be made by the professional gatekeepers who determine eligibility. One carer, for example, described how the final decision on residential care was 'dependent on a panel vote'.

Among those who had leapt this hurdle, it was clear that even where users were emphatic that they alone had made the decision, it was not necessarily a choice between alternatives. This was either because no alternative was offered, or because of the perceived shortcomings of the only alternatives believed to be available. One service user illustrated this very clearly:

'The choice was mine. I chose the home in preference to having the upset of home help changing... I didn't like the disruption caused when they were changed... sometimes they would be allocated half my usual time. What can they do in half an hour?'

Users and carers did, however, refer to having a choice of homes. But even this could turn out to be more apparent than real, dependent on the availability of places. One user, for example, described how she had been waiting for a place in one home but:

'It was made clear to me I would not get a room within (this) home, and I felt I just had to accept this because there was nothing anyone could do.'

Another constraint on 'choice' may be the costs involved both for the users and for the local authority. These interviews with users and carers did not explore charging or their attitudes towards paying for services. These issues are being explored in the follow-up interviews. Workers, however, expressed their concern that people would refuse a service on the basis of cost not lack of need. Thomas (1994) gives some substance to this anxiety in her review of charging policies. But it is not just the cost to the client which may impede choice. Workers were aware that the options available to people being funded by the local

authority were constrained by the costs of different resources. One practitioner, referring to residential placements, commented:

'The family can look around at the homes. They still have the right of choice provided they are within the financial limits we give them.'

In respect of domiciliary care, too, users and carers would not necessarily experience the process as one of 'choosing', as one remarked:

'I didn't choose, you got what was available.'

For some there was some scope for trying out different things, albeit from a limited range. For example, one service user tried meals-on-wheels but did not enjoy the food. The arrangement was changed to a home help coming in daily to prepare and cook meals. Overall, however, the notion that users and carers can pick and choose is undermined by the experience of one carer given the names of five homes for respite care:

'Some were far too expensive, some had stopped taking respite, and some were fully booked up.'

There was also little evidence to suggest that users and carers felt able to determine the timing and extent of the service. One service user, for example, remarked:

'It would be nice if I could have a longer time of home help. I cannot stretch or bend. The home helps have the inclination, but not the time.'

Nor did their accounts suggest they had much influence over the way the service was provided. One service user was happy to have a home help every day, but would have preferred to have a regular person who would 'know your routine and you would know them'. Another for whom, after some delay, a social carer service became available, commented:

'I didn't feel entitled to ask for a type of person who had the same interests as myself.'

The picture which emerges from the comments is of a process whereby the service users and carers agree with what is offered from a fairly

standard list of home help, daycare, respite and residential care. As summarised by one service user:

'It was decided I would get an extra eight hours home help, I was agreeable to this.'

In general, the respondents did not appear to be encouraged to explore different ways of meeting their needs, nor of being given much scope to choose between means. Their experiences would seem to echo those described by Meethan and Thomson (1993), as decision making between *given* services, rather than greater choice between *possible* services.

While carers seeking residential care for the person they cared for appeared to be more active in asking for what they wanted, on the whole both users and carers appeared to be at a disadvantage in knowing what was available, or possible, or what they were entitled to. As such they were inevitably dependent upon the worker. Furthermore, expectations were limited. Only one user interviewed questioned the level of service she was receiving. Referring to the one and half hour's home help she received each week she remarked, 'But I would have thought I was entitled to more'.

Conclusions

In the context of the assessment, the responses of the users and carers interviewed suggest that they felt they were given a chance by the worker to express their needs, and were listened to. In responding to these expressed needs, however, the comments of the workers as well as of the users and carers imply that different voices carry different weights. The loudest voice may prove to be that of the other professionals and agencies determining need and eligibility.

What also emerges from the responses is the degree of dependence of users and carers on the assessing professional: for support at a time of crisis, for information and for access to resources. It has been argued that for older service users, the ceding of power to a professional may itself be a positive choice. Stevenson and Parsloe (1993), for example, suggest that the concept of 'empowerment' needs to be specifically related to the different material needs of very elderly people, and may need to encompass the older person seeking to hand over tasks which

worry them. Along similar lines, Robertson (1993) found that, in recognition of their own powerlessness, older people sought a care manager:

'Who had status, who was able to cope with bureaucracy, had good contacts, was shrewd and assertive (with service providers) and could generally ensure the prompt and consistent delivery of the required care.' (p.16)

This approach does pre-suppose that the workers themselves are unfettered by competing demands, but as has been demonstrated (see, for example, Ellis 1993) workers are not only advocates but allocators of scarce resources, using the assessment as a means for rationing demand. In effect, workers too may bring with them other 'agendas'.

As a result of the tension between the competing imperatives of consumer empowerment and management control, people may feel they are listened to and consulted, but, that at the point of decision making, find that the exercise of power is severely constrained. For older service users and the people who support them, there may still be a long way to go on the ladder of participation.

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